

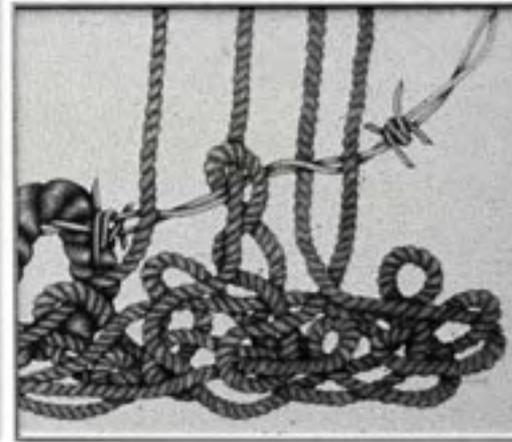
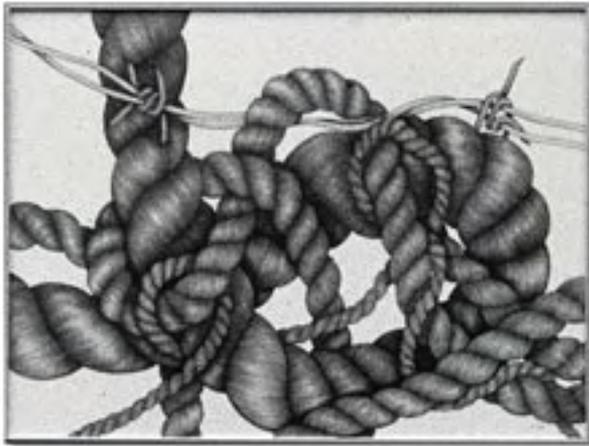
When Is a Pr

B Y M A R T H A J A B L O W

For decades, pain was the “stepchild of MS symptoms,” said Heidi Maloni, an MS-certified nurse and researcher at Catholic University School of Nursing in Washington, DC. Health-care professionals focused on visible problems, like mobility or vision deficits, balance, or bladder control.

“Finally, pain has achieved visibility,” noted Stephen Waxman, MD, PhD, chief of Neurology at Yale School of Medicine and chief of PVA/EPA Neuroscience Center at the West Haven Veterans Hospital. “There’s been a paradigm shift in interest in pain as a therapeutic topic just in the last 3–5 years.”

Art: ©Karen DeWitt
“Tangle”, 1990
Graphite, Prismacolor
60" x 228"



ickle a Pain?

This is driven in part by basic research. Molecular biologists are learning the critical details of how pain works. And it is driven by a new appreciation of the role of pain in health and illness. MS experts recognize that it is common for people with MS to experience pain at some time during their disease. Medical schools now teach pain management and train new doctors and nurses to consider pain a vital sign, along with blood pressure, heart rate, temperature, and respiration. Soon it will be routine for a health-care provider to ask

people to rate their pain on a scale of 1–10, with 1 representing little or no pain and 10 representing unbearable pain.

Different strokes for different folks

For some people, MS pain is a passing tingle. For others, tingling is as violent as the aftermath of a bolt of lightning. Or they live with stabbing, aching, or burning sensations. “Like a lot of things in MS, it’s dramatically variable,” said Debra Frankel, an occupational therapist in Boston and one of the Society’s senior consultants.

“Pain is subjective,” Maloni emphasized. “But there are themes.”

There are two main types of pain. One is musculoskeletal pain. It may come from sitting for long periods (muscles may stiffen), from muscle spasms produced by spasticity, or from physical stress caused by compensating for weakness and poor coordination. Musculoskeletal pain responds to physical therapy, stretching, spasticity medications, and conventional painkillers such as ibuprofen.

The other pain is from lesions along the nerve pathways. This neuropathic pain requires very different treatment. It is caused by nerve damage and can range from a mild prickling to unbearable burning or aching. And as Douglas Goodin, MD, professor of Neurology and director of the MS Center at the University of California, San Francisco, pointed out, “There’s a poor correlation between where brain lesions are located and the symptoms the patient experiences.”

Names for neuropathic pains

“Paresthesia” refers to any abnormal sensation: prickling, tingling, pins and needles, “ants crawling on my skin,” or a tight girdling around the torso, nicknamed “the MS hug”.

“Dysesthesia” refers to paresthesia that cross the line—the prickle or itch that becomes blatantly painful, as well as burning or aching sensations. (However, spasticity and muscle strain each cause aching.)

“Hypesthesia” means numbness, the absence of sensation. Absence often feels like something: people describe having

clown feet or fingers like sausages. Moreover the sense of where one’s body is in space—called proprioception—can be abnormal, causing other weird sensations. MS damage may also transform a gentle caress or the touch of a bed sheet on bare skin into pain instead of pleasure.

“Pain is like a **train** that starts out slowly. If there is little or no intervention, it may pick up speed.”

Dolly Baker, 45, of Mount Laurel, New Jersey, has numbness and tingling, mostly on her left side. “It’s similar to when your foot is asleep,” she said. “Sometimes I wiggle my fingers and the sensation diminishes, but it never completely goes away.”

Philadelphia graphic artist Cindy Elia, 32, reports that her sensations evolved. “I first had itching on the left side of my back. It became intense and spread to the front of my chest. That went away, and now the left side of my chest feels numb and tight. Lately my left foot has gone tingly, and the balls of my feet or the arch of my left foot get numb. When I swim or walk too much, it feels like an itch that won’t go away. But it usually subsides after I stop exercising.

“It’s hard to find someone else with exactly the same symptoms you have,” she added.

Pain management

With this much variation, it comes as no surprise to hear experts say that certain treatments work for some but not others.

Everyone agrees that pain management requires good communication—an essential two-way street between patient and health-care provider.

Dr. Goodin confirmed that he depends on both what his patients report and on what he learns from physical examination. “Pain can’t be measured on an MRI,” he said, “but if patients can’t feel pinpricks or their joints moving, a doctor knows that something’s wrong in their sensory pathways.”

“Pain is like a train that starts out slowly. If there is little or no intervention, it may pick up speed,” observed clinical psychologist Catherine J. Archibald, PhD, assistant professor in Clinical Neurosciences at the University of Calgary, who works at the university’s MS clinic. “Ide-

ally, you want to intervene early when the pain is just starting to chug. Psychological interventions should be included from the very beginning rather than added later when the pain is like a runaway train.”

“Diagnosis is critical because treatment depends on the nature of the pain,” Dr. Goodin said. “If pain is episodic—the one- or two-minute sensation that occurs 30–40 times a day—it may respond to anticonvulsant medicines such as Tegretol (carbamazepine), Dilantin (phenytoin), or Neurontin (gabapentin). If the pain is more persistent, it may respond to one of these medications or to one of the tricyclic antidepressants.”

Antidepressants? Anticonvulsants? People with MS pain don’t have epilepsy—and they may not be clinically depressed. Heidi Maloni explained that these drugs have specific effects on the nerves. Tricyclic



“Sympathetic Response” Mary Ann O’Driscoll



M.S. Simulator

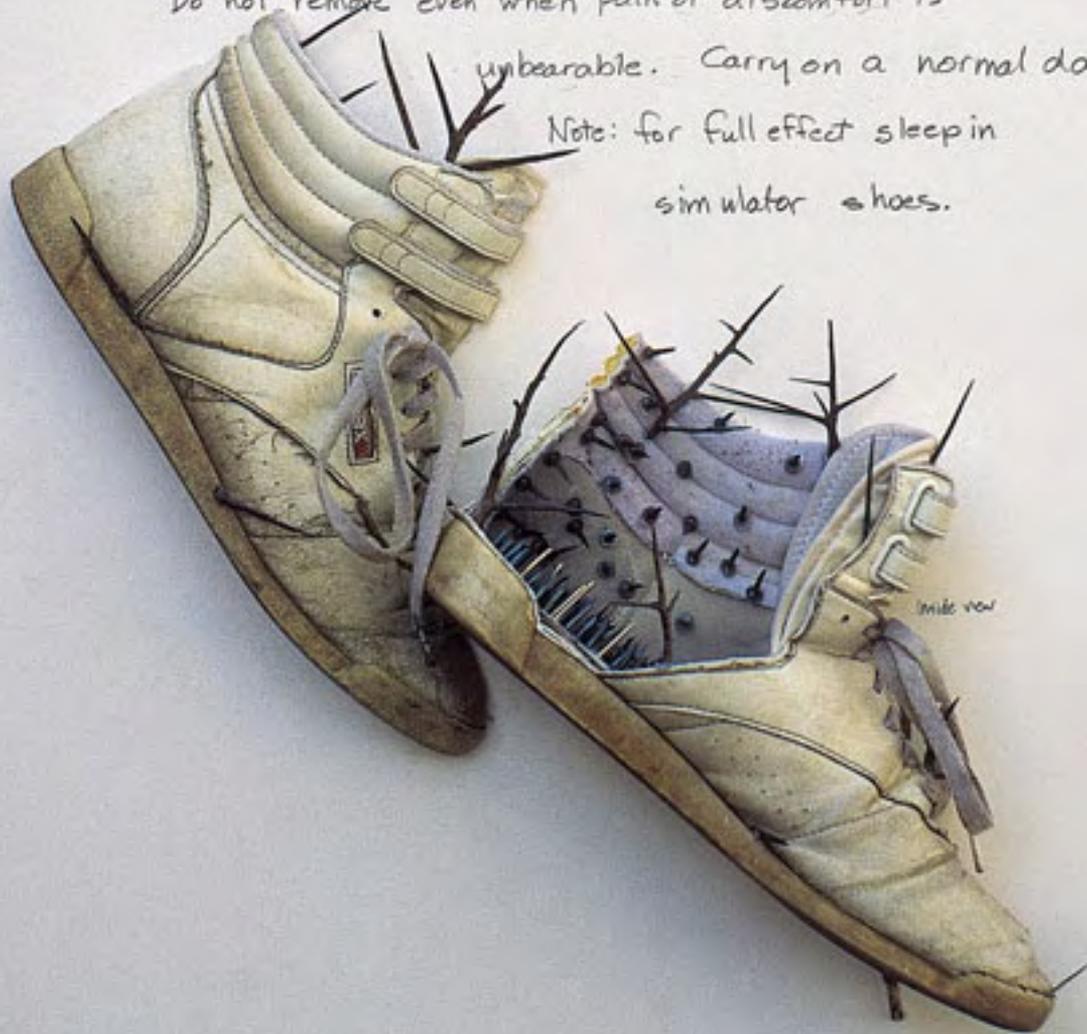
for the feet

Directions:

Wear shoes for a 24 hour period.

Do not remove even when pain or discomfort is unbearable. Carry on a normal day.

Note: for full effect sleep in simulator shoes.



not for the faint of heart

Karen DeWitt

antidepressants (imipramine, amitriptyline, nortriptyline, and desipramine) sedate pain by increasing the body's stimulant chemicals (serotonin and norepinephrine). Anti-convulsants block sodium channels on nerve fibers and inhibit the flow of calcium into nerve cells. This modulates the experience of pain.

Maloni and other pain specialists emphasize the importance of preemptive medication: "Medicate by the clock, not by the event of pain," she said. "And don't stop when you're free of pain. Take what is prescribed for at least three months. Then talk to your doctor about a drug holiday to see if the pain is gone."

Add-ons

At her Los Angeles MS center, Barbara Giesser, MD, associate clinical professor of Neurology, University of California at Los Angeles (UCLA) School of Medicine, finds that topical treatment may complement pain medications.

"For localized pain, I sometimes suggest ice packs or over-the-counter skin creams with capsaicin—the stuff in red hot peppers. Or I may prescribe a lidocaine cream or a lidocaine patch."

Dolly Baker, whose tingling and numbness are worse in the winter, applies

heat using an herbal heating pad. "I throw it in the microwave to warm it up. Then I wrap my hand in a towel before I put it on so I won't get burned. I also wear a glove, even in the house."

Cindy Elia prefers cold. "I try everything to stay cool. I'm also learning to ignore the numbness by focusing on other things."

To diminish pins and needles, some people wear pressure stockings. For hypersensitive feet and legs, Debra Frankel suggests wearing lambskin booties to bed or using "bed cradles", little wire tents that keep sheets and blankets from touching the skin.

Massage, acupuncture, hypnosis, and acupuncture all help some people but don't work—or even exacerbate—pain for others.

How pain snowballs

Fear magnifies pain, so it is important to know that the intensity of pain has little to do with the course of MS. It does not mean the disease is worsening, the specialists agree. But there are many other factors that intensify pain.

"Pain is not just what's going on at the level of the neuronal pain receptors," Dr. Archibald said. "A person might have catastrophic thoughts: 'Oh no! This is awful! I can't do anything about it!'" Dr. Archibald described "pain behavior": When pain becomes the focus of attention, a person's sense of control and self-efficacy can be undermined. Pain often makes people reduce activity



Karen De Witt, a visual artist living in Illinois, was diagnosed with MS in 1987, a fact that has clearly influenced her art. "I am not trying to 'tell a story' or 'set a mood'," she writes, "but rather to expose an otherwise unseen, unnoticed facet of my subject." Her work is included in major collections worldwide.

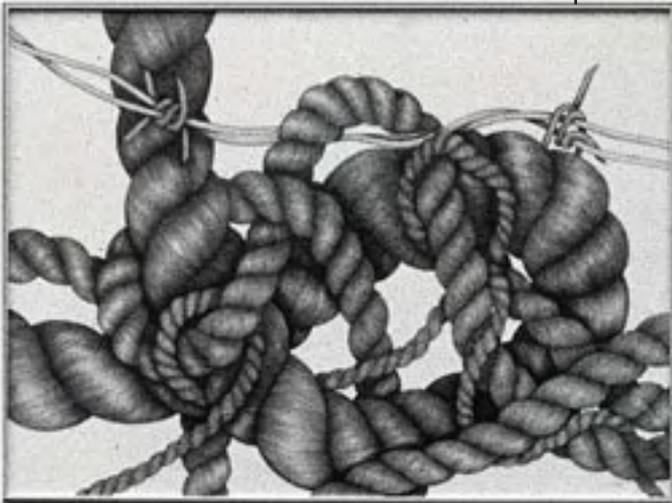
and interactions with others. And pain behavior influences how other people treat the person in pain. Some family members think they help best by encouraging only rest—and this may increase the individual’s inactivity and isolation.

“Many other factors can make pain snowball, including MS-related fatigue, mobility limitations, or mood disturbances,” Dr. Archibald pointed out.

Making the snowball melt

The vicious cycle of pain and pain behavior, leading to an increasingly narrow life, can be broken. “With the assistance of health-care professionals, people can develop personal pain-management programs,” Dr. Archibald said.

“They may draw from a large menu, including medications, topical treatments, physical therapy, use of community resources,



and activities such as yoga, tai chi, swimming, biofeedback, meditation, or visualization. Individual and family counseling can help people change pain behaviors and learn to pace their activities.

“Collaborating with professionals empowers the person with pain to be the ‘chef’—selecting appealing ingredients and regaining some control.”

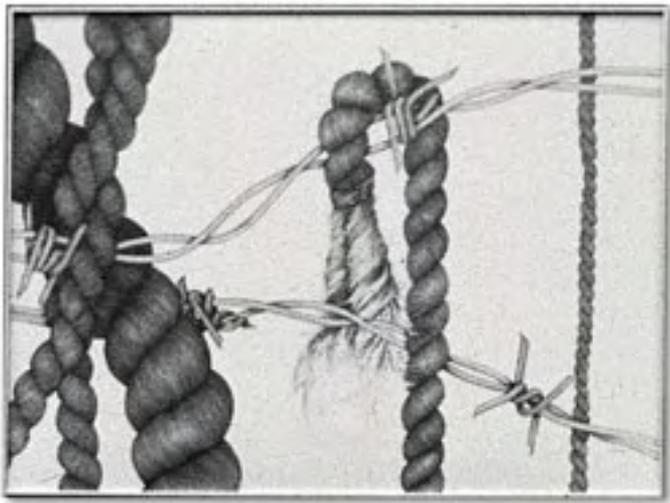
Behavior as a family affair

Dr. Archibald treated a man in his mid-40s whose severe pain, along with disabling fatigue and mobility limitation, left him spending most of his days lying in bed looking out the window. Comprehensive medical treatment addressed some of the contributing factors. Dr. Archibald focused on helping him and his wife reduce the impact of the pain.

Taking a behaviorally oriented approach, she and the couple made up a

“Collaborating with professionals empowers the person with pain to be the ‘chef’—selecting appealing ingredients and regaining some control.”

list of things he would like as rewards. To outsiders, it might sound silly, but, at the beginning, if he dried dishes for five minutes, he got his favorite red licorice or a foot massage as a reward. His wife learned to encourage him, and yet leave room for “no activity” due to bad days. He tried for fewer “no activity” days, even if that meant doing something for a very brief period of time. He did things slowly and in small steps, but he and his wife said the “small-step” process was fun and motivating. Soon, activity became its own



reward. He rediscovered an old hobby, woodworking. He gradually spent more time with his wife and children, and his depression began to lift.

These days he goes out, traveling to the hardware store for supplies and the post office for mail. He swims once a week and enjoys the cool water, which may relieve his burning sensation. This psychological approach did not reduce the severity of his pain, but it significantly reduced how it was affecting his life.

Pain has “come a long way, baby ...”

“Occasionally, people may still hear, ‘You’re not in pain. MS doesn’t cause pain,’” Dr. Giesser said. It isn’t true. But it is possible that a pain is not MS. As Dr. Giesser pointed out, “It could be a pinched nerve, a sprained muscle, or the sign of some other medical problem. That’s for a physician to figure out. It’s important for people to tell the physician about pain.

“People can be reluctant to discuss something their doctor hasn’t asked them about. Pain happens and something can be done about it!” she stressed.

If pain is a regular companion, some experts recommend keeping a “pain diary” to record the type, location, frequency, duration, and related events that trigger or relieve it. The purpose is not to obsess about pain, but to make a record of triggers and the strategies tried. “Sharing is a relief in itself,” Heidi Maloni said. Moreover, the diary may hold clues to better control.

A brighter outlook

In the future, pain relief will be more precisely targeted, Dr. Waxman predicted. “When I was in medical school, we were taught that there was only one type of sodium channel. Now we know there are 10 different sodium channels, each of which opens and closes differently.

“Sodium channels act as molecular batteries,” he explained. “When they turn on, they cause nerve cells to fire. We’re finding out which sodium channels are firing inappropriately along the pain pathways. The next generation of medications,” Dr. Waxman believes, “will work by turning off the molecular generators of pain.”

It may then be possible to stop chronic burning, stabbing, aching, or itching as definitively as snapping off a light switch. Until then, the chef model rules. People with MS will manage pain with medications, home remedies, mental-health support, activities, and as much hope and humor as they can muster. ■

Martha Jablow wrote about accessible gardening in our Spring 2002 issue. (Go to www.nationalmssociety.org/IMSSp02-Contents.asp.)